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ABSTRACT

There is a current trend towards maintaining dementia patients at home and postponing institutionalization as long as possible. Previous research has suggested that frequency of help and support received by the caregiver is more predictive of burden than memory or behavior problems of the patient. Burden and distress were investigated using a sample of husbands (N=14) and wives (N=15) who served as caregivers to a demented spouse. Results from standardized instruments and qualitative questions revealed that the quality of social support was the best predictor of burden and distress for both husbands and wives. Memory and behavior problems were more important to wives while current functioning in the family role was more important to husbands. The measures suggest more variance for burden than distress, indicating a common subjective dimension. (Author/JAC)

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FAMILY RELATIONSHIPS AND BURDEN IN LONG-TERM CARE

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Most older persons with senile dementia continue to reside in the community (Bergmann, Foster, Justice & Mathews, 1979). There may be as many as three times as many dementia patients in the community as in institutions (Kay, Beamish & Roth, 1964), often with symptoms as severe as those who are instititonalized (Lowenthal, Berkman & associates, 1967). Family members usually provide assistance to the dementia patient to enable them to be maintained in the community, at considerable emotional and physical cost to themselves.

There are not, as yet, effective treatments for the diseases that comprise the senile dementias. In a review, Eisdorfer and Stotsky (1977) found no drug that significantly and consistently was associated with improvement in functioning. Research continues to be done, both in trying to understand etiologies and the process of change that occurs in brain structure for the purpose of uncovering a pharmacological intervention.

Psychotherpay is not often done with dementia patients because of their short-term memory deficits. However, some authors feel that supportive counseling may provide some relief, especially in cases where the impaired person has some awareness of his problem and is suffering from depression because of it (Gurland, 1979; Zarit, 1980).

In the absence of effective treatment for dementia, the issue becomes one of long-term management. Different families have differing abilities to tolerate stress, and institutionalization is often proposed as a solution. However, some studies report high rates of mortality among those with low daily functioning who are relocated compared to those who remain at home (Blenkner, 1967; Borup, et al., 1979, 1980). Nursing homes are extremely costly as

well, and dementia has been excluded from Medicare coverage. Consequently, for both humanitarian and economic reasons, finding alternatives to institutionalization has been a continuing theme in geriatric mental health literature (Kahn, 1975).

When a senile dementia patient is maintained at home there is usually one person who serves as the primary caregiver, usually the spouse or a daughter. The caregivers, then, are the pivotal persons, for when they become so stressed that they can no longer continue to provide care at home, insitutionalization usually follows.

Some attempts are now being made to prevent this from happening by developing alternative means of support for caregivers (Zarit, Reever & Weston, 1980). In order to assist caregivers, it is necessary to understand the behavior problems they encounter. One study, by Sainsbury and Grad de Alarçon (1970), attempted to determine which behaviors are most troublesome. They identified behaving oddly, potentially harmful behavior to self or others, restlessness, and being troublesome at night as the most frequently mentioned behavior problems and Lowenthal (1964) found these same behaviors as predictive of institutionalization. Sanford (1975) found that lack of time for themselves and sleep disturbance were the most difficult behaviors for caregivers to tolerate.

Reever & Bach-Peterson (1979) attempted to measure the impact of these problem behaviors on the subjective feelings of burden experienced by the caregiver. They used a sample of community-dwelling dementia patients and used a structured interview and several self-report measures. They found that subjective burden was not greater among spouses than children, but that self-report of psychiatric symptoms

showed significantly more distress for spouses.

The relationship between specific problem behaviors and the subjective experience of burden and distress is not a clear one. Zarit, Reever & Bach-Peterson (1980), report no relationship between feelings of burden and the extent of behavioral and mental symptoms. Burden was found to be associated with social support, mainly with visits from family members. The measure of subjective burden, called the Burden Interview, had not been validated nor had possible mediating factors been investigated, which is what the present study proposes to do.

Whether the dementia patient is husband or wife, father or mother, may have some impact on both problem behaviors and experienced burden. While quantitative studies are lacking, clinical observations have found consistent differences in complaints when the dementia patient is a husband as opposed to when it is a wife (Weston, 1980). Wives complain that their husband follows them around and is dependent, and that handling money and driving are problems. Husbands as caregivers are more likely to complain about assuming household responsibilities and about their wife's inactivity and inability to interact with them. There would seem to be personality changes as well as changes in specific behaviors that add to the caregiver's distress. The quality of the relationship prior to the onset of the disease seems to be an important factor, as well as the dementia patient's ability to continue to provide positive feedback or gratification and to in some way acknowledge the caregiver's efforts (Weston, 1980).

A better understanding of the subtleties of personality and behavior changes that occur over time with dementia patients would add greatly to the development of appropriate counseling and interventions for caregivers. If there is a specific set of behaviors that can be

expected when a husbands gets dementia and they are different from a wife who gets the disease, then different treatment strategies can be employed. Furthermore, one of the most stressful aspects of the disease for caregivers is its very unpredictability. By investigating the complexes of behaviors in a systematic and consistent way it might eventually be possible to predict certain courses of behavior in particular indidivuals.

Individual variation in symptom patterns is felt to be great in dementia patients (Kahn & Miller, 1978). Only moderate correlations have been found between brain structure changes, such as senile plaques and behavior change (Roth, Tomlinson & Blessed, 1967). Such reports have always stressed that there were a number of cases that were an exception to the pattern, for instance persons with massive cerebral damage and minimal behavior change and others with minimal brain impairment and extensive behavioral deficits typical of dementia (Kahn & MIller, 1978). Brain functioning is on y one contributor to behavioral functioning, and for some individuals the other factors, such as education, work, personality, adaptive responses, attitude, motivation or verbal fluency can compensate for compromised cerebral functioning.

Despite variations between people, some generalizations can be made. In order not to lose the important information contained in the variations between people while looking for the similarities, an idiographic approach to studying personality has been proposed by some researchers (Bem & Allen, 1974; Zarit, 1980). In the present paper, a measure has been developed, the Family Change Measure, that uses this idiographic approach to understand the individual variations in symptom and behavior patterns.

Subjects: The current paper represents the first half of data collection in this project. To date, 15 wives of dementia patients and 14 husbands have been interviewed. The total sample will consist of 30 wives and 30 husbands. An adjunct study will also look at daughters as caregivers. Husbands and wives as caregivers were significantly different in age, with husbands an average of 10 years older (See TABLE I). The dementia patients, however, were nearly the same age, around 71 years old. There was no difference in level of education between the two groups of caregivers, but there was almost a three year difference between the dementia patient groups reflecting that cohorts relative difference in educational opportunities between the sexes.

Marriages in the sample had for the most part been long, with means of about 35 and 45 years.

Contact with dementia patients was limited to the administering of the Kahn 10-item Mental Status Questionnaire [MSQ] (Kahn, Goldfarb, Pollack & Peck, 1960) and the Face-Hand test (Bender, 1952; Fink, Green & Bender, 1952). There were some differences between the impaired spouses. Impaired husbands scored an average of 3.8 on the MSQ and 9.07 on the Face-Hand, while impaired wives scored 2.23 on the MSQ and 5.75 on the Face-Hand. This difference is significant clinically, although not statistically because of the large variance involved. The number of years of memory loss and probable severity were not significantly different between groups.

Measures: The measures were focused on the dementia patient, although the information was gathered from the caregiver in an interview. Included were the Family Change Measure, the Burden Interview, the Memory and Behavior Problem Checklist, a qualitative measure of social support, the Brief Symptom Inventory and the contents of a semi-structured interview.

a. Family Change Measure (FCM)

This measure was developed specifically for this study in order to quantify the relationship variable. It consists of 49 items in six different areas: financial, social, household, transportation, emotional and intellectual. The items were derived from clinical interviews with caregivers of dementia patients. For each item caregivers were asked who performed that function before the onset of the illness: their spouse, themselves, both of them or neither. Of the items previously done by the spouse or by both of them, they were asked to rate the current level of functioning of the spouse and how important it was to them that the spouse be able to perform it. The score being used in this paper was derived by dividing the Total Current Functioning score by the total number of items done by either the spouse or both of them, giving a mean level of current functioning [FCM Mean].

b. Burden Interview (BI)

The Burden Interview was developed to determine to what extent caregivers perceive their involvement as affecting their financial status, physical health, emotional health, and social and recreational activities (Zarit, Reever & Bach-Peterson, 1980). The interview consists of 20 items, to which caregivers are asked whether

or not they agree. Responses range from "not at all agree" to "agree strongly." A total score is calculated.

c. Memory and Behavior Problem Checklist (MBPC)

Behaviors of dementia patients can be upsetting. Caregivers may have strong emotional reactions to specific instances of problem behaviors, such as when their relative asks repetitive questions or misplaces an object in the house. In order to measure caregiver's reactions to problem behaviors, the Memory and Behavior Problem Checklist was developed (Zarit, et al., 1980). It lists common memory and behavior problems of dementia patients and asks how frequently the behavior occurs and how well the caregiver can tolerate the behavior when it occurs. Activities of daily living (Lawton, 1971) are also included in this measure. The score that will be used in this paper is the total frequency of memory and behavior problems (MBPC Frequency).

d. Quality of Social Supports

A qualitative question about social support was asked. Caregivers were asked which statement best reflected their current situation overall: "I feel overwhelmed and don't know where to turn," "I know I could get more help but don't know how to ask," "I'm getting some help but could use more" or "I'm able to get most of the help I need."

e. Brief Symptom Inventory (BSI)

The Brief Symptom Inventory was used to measure emotional distress (Derogatis, Lipman, Covi, Rickels & Uhlenhuth, 1970). It consists of 53 items covering common complaints of psychiatric outpatients. These items are likely to reflect stresses involved in caregiving. The checklist items are answered in terms of how subjects felt during the past week. The mean distress level has been found to be the best measure

of overall distress.

f. Interview

The measures were presented in an interview, as well as other questions covering demographics, the history of the illness, and a question asking the caregiver to rate on a scale from 1 to 10 the likelihood of institutionalizing the dementia patient within the next year.

Results: One of the main questions fo this study was whether prediction of burden or distress would be improved by considering husbands and wives separately rather than evaluating them together. As you can see in TABLE II, the explained variance is not different for the Burden Interview, but more variance is explained for wives on the measure of distress. More important, the ordering of variables is consistently different for husbands and wives, with memory and behavior problems more important than family change for wives and the opposite for husbands. However, the quality of social supports is the most important variable for both, supporting the findings of Zarit, et al.,(1980). Husbands did report a slightly higher level of social support, 2.36 compared to 1.60 for wives. And wives report slightly lower mean current functioning, 3.09 compared to 3.23 that the husbands report.

Discussion: One of the aims of this study was to replicate the findings of the earlier burden study of Zarit, et al. (1980), and for the whole sample and for both husbands and wives, the quality of social supports continue to be the best predictor of burden and in the same magnitude. Social supports are more important than actual impairments or changes in their role in the family, although both contribute significantly. Husbands were somewhat more likely to have

gotten household help, while wives were more likely to have confidants and not to utilize available helping resources.

The present study was designed to lend empirical support for clinical hunches, with the ultimate aim of using this information in the development of interventions with caregivers. Husbands have been more likely to come into the counseling situation seeking specific answers to their questions or specific questions. Wives are more likely to come in wanting "relief", "help", and have more global, less focused complaints. In light of this, their higher reported level of burden is not surprising.

It is hoped that when the data collection is completed it will be posible to identify which of the three areas, memory problems, social supports or family change, contribute the most to the experience of burden and distress, and it is anticipated that there may be several individual patterns within the groups of husbands and wives. Based on the current data, counseling centered on building more extensive social support systems would be most useful, followed by dealing with memory and behavior problems for wives and family changes in responsibilities for husbands. In either case, meeting these needs is important in allowing caregivers to continue to provide care in the community and postpone institutionalization.

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TABLE I

MEAN DIFFERENCES BETWEEN HUSBANDS AND WIVES ON DEMOGRAPHICS AND MEASURES

DEMOGRAPHICS:	HUSBANDS (CG)	WIVES (CG)
Age	73.43	63.47**
Age of Spouse	71.14	70.80
Education	14.46	14.00
Education of Spouse	13.21	16.00*
Years Married	44.86	34.67**
MSQ (Mental Status)	2.23	3.80
Face-Hand test	5.75	9.07
Years of Memory Loss	5.78	5.20
Probable Severity (2=Moderate, 3=Severe)	2.64	2.33
RESULTS:		
Memory and Behavior Problem Checklist Total Frequency	47.36	40.33
Family Change Measure Number Spouse Items	11.07	12.40
Number Both Items	13.93	16.47
Total Mean Current Functioning (3=Can do occasionally;4=Never)	3.23	3.09
Quality of Social Supports	2.36	1.60
Burden Interview	32.57	44.93**
BSI Mean Distress Level (1=a little bit; 2=moderately)	1.68	1.75
Likelihood of Institutionalization in next year (scale 1-10)	1.68	1.75

* $p < .05$

** $p < .01$

TABLE II

MULTIPLE REGRESSIONS: DIMENSIONS OF BURDEN AND DISTRESS OF CAREGIVERS

BURDEN

Whole Sample:	r_o	R	R^2	R^2	Beta
Quality of Social Supp.	-.60	.60	.36	.36	-.61
FCM Mean	.09	.61	.37	.01	.10
MBPC Frequency	.19	.61	.37	.00	-.03
Wives:					
Quality of Soc. Supp.	-.49	.49	.24	.24	-.58
MBPC Frequency	.36	.57	.32	.08	.50
FCM Mean	.36	.59	.35	.03	-.31
Husbands:					
Quality of Soc. Supp.	-.54	.54	.29	.29	-.52
FCM Mean	.23	.56	.32	.03	.21
MBPC Frequency	.08	.57	.32	.00	-.06

DISTRESS

Whole Sample:					
Quality of Soc. Supp.	-.41	.41	.17	.17	-.46
FCM Mean	-.01	.42	.18	.01	-.21
MBPC Frequency	.00	.44	.19	.01	.14
Wives:					
Quality of Soc. Supp.	-.54	.54	.29	.29	-.59
MBPC Frequency	-.08	.57	.32	.03	-.13
FCM Mean	.16	.57	.32	.00	-.06
Husbands:					
Quality of Soc. Supp.	-.25	.25	.06	.06	-.28
FCM Mean	-.13	.30	.09	.03	-.36
MBPC Frequency	.10	.39	.15	.06	.32

FCM= Family Change Measure
MBPC= Memory and Behavior Problem Checklist
Quality of Soc. Supp.= Quality of Social Supports